
Book reviews

Mental Handicap – Partnership in the Community

Jean Taylor, 36 pages, London, £1.50, Office of Health Economics/Mencap, 1986

Given current developments in our perceptions and care of the mentally handicapped, it is difficult to identify the particular contribution which this publication by OHE/Mencap makes; it is strong on sentiment and opinion but weak on evidence, raising more questions than it answers.

The author, Jean Taylor, has documented changes in attitudes towards the mentally handicapped and the pattern of care provided. She outlines trends in reported incidence and prevalence, examines possible causes and available measures for prevention. She looks at current service strengths and weaknesses and makes recommendations for future improvement. For severe mental handicap these include fetal screening, offering abortion when necessary, supporting all pregnant women better, particularly those most at risk of producing low-birthweight babies and providing 'good' community care for the remaining severely mentally handicapped, with support for families and carers and close involvement of statutory and voluntary agencies. She advocates an integrated National Health Service/Local Authority (NHS/LA) register to facilitate planning. For the mildly mentally handicapped she advocates political, fiscal and social remedies involving redressing 'disadvantages'.

It is a pity that the author has not researched the likely effectiveness of her recommendations in as much detail as she has researched the historical aspects and background. She should have attempted to demonstrate how her

recommendations could be both feasible and effective. Even the 'fact' boxes interspersed between diagrams and text contain unsubstantiated opinion.

The publication raises several major ethical issues. Widespread case registers are advocated as used in Sheffield and Wessex and even an integrated NHS/LA record-linkage scheme. This would provide comprehensive information which in the author's opinion would significantly improve national planning. The author has failed to demonstrate why it would either improve planning nationally, at a time when the emphasis is on local planning for a normal life, or even why such registers are necessary locally. Existing registers such as the Sheffield register, which have a very small minimum data set may not pose as many ethical or confidentiality issues as others containing a breadth of information such as diagnosis, level of functioning, behavioural characteristics (often unstandardised, with no control of variability) and detailed information on social circumstances and on the presence of perceived mental illness. Individuals' and families' rights regarding their documentation in, and information divulged from, such a register must be protected. It would seem morally appropriate to allow individuals to opt out of being included in a register at all, in which case the use that could be made of the resulting incomplete register would be compromised. The linkage of such an incomplete, unstandardised local register into one national database would pose even more problems, both of confidentiality and of incompleteness. Evidence would suggest that the confidentiality problems of registers escalate with growing numbers of informants and users. The use of a national database, if confidentiality were to be preserved, might have to be restricted to a very few

users, as with the current national AIDS information system, run by the Communicable Disease Surveillance Centre (CDSC). In this case, would any purpose be served?

The author has also failed to demonstrate why more outreach to and support of pregnant women will work as a means of preventing low birthweight and mental handicap and also why political, fiscal and social measures will necessarily improve the functional abilities of the mildly mentally handicapped. More general support was advocated in the Black Report as a measure for prevention of disease in children. It is likely that more resources and support could be channelled into preventing any causes of ill health in humanity. More resources for mental handicap prevention may mean less for, say, AIDS prevention. The ethics of such a choice is presumably beyond the scope of this book.

Whilst urging the adoption of national targets for prevention of severe mental handicap, the author cannot state what they should be except in general terms. The publication walks through an ethical minefield in its discussion of screening and abortion as major preventive measures. Why, states the author herself, when the paper is based on the premise that individuals with mental handicap have the same right to life as all other members of the population, should it be acceptable to abort a fetus simply because it is 'abnormal'. One solution put forward is a free choice regarding termination for all mothers and their partners. Yet this raises further ethical problems including that of fair allocation of resources.

Will the preventive measures put forward in this paper work? Given acceptable unit costs, the author advocates prenatal fetal screen for all women aged 35 and over and for women in high-risk groups below this age. How morally acceptable is it to differentiate

between women in terms of probability of risk to an unborn child and offer a test which, to be effective in population terms, will lead to being offered termination of an abnormal fetus. Such screening would generally be for Down's Syndrome and would only be performed after agreement of the mother to abort an affected fetus. To respond to a woman's request for such tests may be morally acceptable, but to sow seeds of doubt in the mind of a pregnant mother who hitherto had no worries, and to offer her the death of her baby as the sole solution may be ethically unacceptable.

There is no evidence put forward as to who these high-risk women are, nor of the proportion of women in these groups likely to find this method of prevention morally or ethically acceptable. It would have been interesting to have examined the acceptability and efficacy of such programmes elsewhere. In addition, one would have expected a health economist to have looked more closely at the issues of likely cost-effectiveness of such a screening policy. The application of currently accepted criteria for monitoring a screening programme would have been illuminating.

Despite these reservations, the author reflects a body of current opinion, concerned to make things work, to provide 'good' community care, though possibly at the expense of families and the community, and to involve statutory and voluntary sectors more in working together. The problems have been realistically analysed but a lot more effort must be directed to finding convincing and ethically acceptable solutions.

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The Physician and the Hopelessly Ill Patient: Legal, Medical and Ethical Guidelines

Society for the Right to Die, 92 pages, New York, \$5.00, Society for the Right to Die, 1985

This volume is divided into three sections. The first, short section is a reprint of an article which was originally published in *The New England Journal of Medicine* in 1984 and is a synthesis of

the thinking of ten American physicians. This article was written in an attempt to begin to examine publicly the responsibility of physicians towards the hopelessly ill patient. The article deals with the ethical dilemmas of whether life should be sustained at all costs or whether its quality should be taken into account. It perceives four general levels of care which should be considered and discussed with the patient ranging from emergency resuscitation to general nursing care which simply makes the patient comfortable. The article considers both the competent and incompetent patient and argues for a sensible approach to patients and relatives who, if at all possible, have the right to be involved in any decision-making. Further, it affirms the limited usefulness of 'The Living Will' as a real assistance to the physician trying to ascertain the best course of treatment for the dying patient.

The second section of the book is a compilation of questions and answers on legal aspects of allowing patients to die. Here the book moves from the ideal or theoretical to the pragmatic. This begins to put into perspective what courses of action are possible, when the patient's wishes should be heeded and the doctor's responsibilities when dealing with the hopelessly ill person.

The final section of this book takes the questions a stage further by giving an up-to-date resumé of right to die and living will legislation and case law State by State. What becomes apparent from this is the sheer complexity and variance in legislation in the United States. Since 1976 some 36 States have enacted living will laws. Although these share common features no two are precisely identical. This is further complicated by the fact that where a State has no legislation or case law about the right to die. . . 'the law of other States may exert influence and may indicate general trends, but it is not binding'.

This book is a fascinating vignette on how the United States is dealing with one of the most important ethical considerations of the medical profession; the right of anyone to self-determination at the most profound level. It is generally accepted that in a developed society ethical principles will be enshrined in legislation. However, reading this book gives one a sad reminder of the chaos which ensues when a medical profession is beset by rampant and costly litigation.

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The Right to Die – Understanding Euthanasia

Derek Humphry and Anne Wickett, 353 pages, London, £15, The Bodley Head, 1986

The uncomfortable paradox of modern medical advance is that technology can often create much suffering particularly in a terminally ill, elderly patient who would much prefer 'to go to sleep now' as in the reported last words of 92-year-old Lord Stockton, Harold MacMillan. To go gently into that good night is the preferred way of death for most of us but the dilemma of modern medicine is that the ethical insistence on the sanctity of life often means for aged patients who might have slipped away peaceably only a generation ago, that death is a technological battle to keep patients alive – no matter what the quality of life is. The medical and ethical commitment to preserving life even against a suffering incurable patient's wishes is the subject of *The Right to Die* by Derek Humphry and Anne Wickett.

This wide-ranging and closely argued study, subtitled *Understanding Euthanasia*, traces the historical perspective of 'mercy-killing' and the roots of the religious and cultural concept of the sanctity of life.

The authors make no secret of their position and argue fluently that euthanasia is the compassionate response where terminally ill but competent people request help to die. It is inhumane, they argue, to keep people technically alive when they are in a hopeless condition, when they are suffering and when they have made it clear they wish to die.

Derek Humphry, an English journalist who now lives in America, writes from first-hand experience in that in 1978 he wrote *Jean's Way*, an account of how he helped his terminally ill wife to die. He was investigated by the Director of Public Prosecutions as to his role in his wife's death but he was not prosecuted. Now with Anne Wickett, his co-author, he has founded the Hemlock Society which urges the rights of people to be helped to die, either in a passive or even in an active way, when medical help can only prolong what they consider to be 'dying' and not living.

However, the study gives a fair and objective view of the many arguments against euthanasia, as an Orwellian